ABSTRACT

Objetives: to describe the social representations of users living with HIV/AIDS about antiretroviral treatment and analyze its implications for adhesion. Method: qualitative study, which data were collected in 2012 by means of semi-structured interviews performed with 10 subjects. It was used the technique of content analysis as analytical resource and Social Representations as a methodological theory for the interpretation of the data. The research was approved by the Research Ethics Committee, Protocol 015718/2011-11. Results: it were showed in two categories: 1. << Treatment with ARV is encountering difficulties >> 2. << Treatment with ARVS is feeling better, is to have quality of life >>. The subjects understand the importance of medicines, however, there are factors linked to their social relationships and feelings that may influence the adhesion. Conclusion: the assigned representations can collaborate for the systematization of nursing care facing the group studied under a brand new view and for the formulation of effective interventions in the aspect of adhesion. Descritores: HIV; Acquired Immunodeficiency Syndrome; Adherence to Medication.

RESUMO


RESUMEN

Objetivos: describir las representaciones sociales de los usuarios que viven con el VIH/Sida sobre el tratamiento antirretroviral y analizar sus implicaciones para la adhesión. Método: estudio cualitativo, cuyos datos fueron recolectados en 2012 por medio de entrevistas semiestructuradas realizadas con 10 sujetos. Se utilizó la técnica de análisis de contenido como recurso analítico y las Representaciones Sociales como teoría metodológica para la interpretación de los datos. La investigación fue aprobada por el Comité de Ética en Investigación, protocolo 015718/2011-11. Resultados: se evidenciaron en dos categorías: 1. << Tratarse con ARV es depararse con dificultades >> 2. << Tratarse con ARV se sentir mejor, es tener calidad de vida >>. Los sujetos comprendieron la importancia de los medicamentos, sin embargo, hay factores vinculados a sus relaciones sociales y sentimientos que pueden influir en la adhesión. Conclusión: las representaciones asignadas pueden colaborar para la sistematización de los cuidados de enfermería voltados para el grupo estudiado bajo una nueva mirada y para la formulación de intervenciones eficaces en el aspecto de la adhesión. Descritores: HIV; Síndrome de la Inmunodeficiencia Adquirida; Adhesión a la medicación.
INTRODUCTION

The main objective of the Antiretroviral Therapy of High Activity (ARVT) focuses on restore, the immunity of people living with the Human Immunodeficiency Virus (HIV), increasing their quality of life. The ARVT, therefore, significantly reduces mortality and the number of hospitalizations by opportunistic infections, in addition to causing significant benefits on physical health of infected individuals, allowing them to resume and make their life projects. 1-2

Despite the excellent clinical results observed in several studies, the researchers consensus about the subject is that these benefits can only be achieved through proper adherence to treatment. 3-4 This exists because the therapeutic failure, resulting often in addition to the biological factors, such as using irregular, insufficient doses or not following the routines for the absorption of drugs, is responsible for resistance and defects in the suppression of viral replication, in addition to immune failure, which causes a drop in quality of life, within the individual, and the risk of spread of strains resistant to anti-retroviral drugs (ARV), under collective, limiting future possibilities of treatment of patients. 4-6

In the literature, several concepts about the adherence term are singled out. Although many scholars still link that expression only with medications, the same can be apply to other aspects related to the health service, as the fact of following a diet or modify certain habits of life. In this context, the adherence to the treatment must be regarded as an action that goes beyond simple intake of medicines, which includes access to information and clarification of doubts concerning the pathology and the ARV, monitoring the individual's clinical-laboratory, the adequacy to the customs and individual needs and sharing of decisions concerning the own health, including for people who don't make use of the therapy. 1,4-6

Despite all the knowledge about the factors that interfere in the adherence to ARVT by individuals, not adhesion still constitutes a challenge and a threat to both individual health and for public health throughout the Brazil. 3-4 In services, this situation generates discomfort in health professionals, who sometimes, feel difficult to understand what lies behind the non-adherence. 6-7

HIV and its impact on the organism are still reflecting on people an impulse for the development of certain negative social representations, ensured many times by the uncertainties regarding the dynamics of the epidemic, which pertain to the epidemiological aspects. Therefore, the socially acquired beliefs and intentions of patients can be used as one of several causal explanations for the attitude-behavior of these in relation to the conduct of therapy. 6-7

One of the theories that propose the study and critical thinking about the interaction of individuals with their environment, as social subject, Social Representations, proposals by Moscovici and introduced in the field of Social Psychology in the Decade of 60, consist in a way of observing the complex phenomena in action in society which are organized under the appearance of a know that says something about the state of reality and that is shared by members of a same group, is characterized for being a guide to analyze certain habits and everyday exchanges. The theory also offers conditions for people to identify imbalances and related to their problems and symbolic elaborations. 8

The approach of the Social Representations Theory also suggests that, in the area of health, to grasp the process of assimilation of information, it is necessary to consider the systems of concepts, values and models of thought and conduct that individuals apply to take ownership of the objects of their environment, particularly those who are new, as is the case with Aids, emerging in the years 80. 6-7

Taking into consideration that compliance with therapy needs to be considered as a complex phenomenon which should not be restricted only to aspects of rational logic and objective, and should also be considered the deep influences of sociocultural and subjective nature of every individual who lives with HIV and who is in treatment, since this always turns out to develop strategies for combating the disease, this research focuses on the following guiding questions: What are the social representations of people living with HIV/Aids about their treatment with ARV drugs? In which way the social representations assigned may imply about adherence to ARVT among these people?

In turn, this study aims to describe the social representations of people living with HIV/Aids about their treatment, as well as analyze the implications of social representations assigned by individuals about their accession process to ARVT.

METHODOLOGY

This article has been extracted from the Monography << Social Representations about HIV/Aids and antiretroviral therapy:...
implications for treatment adherence of users from a specialized service.>

Qualitative study, developed with 10 people living with HIV/AIDS in use of ARVT registered in a Specialized Assistance Service (SAE) of the city of Maceió (AL), northeastern Brazil. The site was chosen to represent one of the largest units of health care to people with HIV/AIDS in Alagoas in respect to the number of outpatient attendances.

Were taken into consideration the following inclusion criteria: individuals living with HIV/AIDS aware of their diagnosis, treatment with ARVT for at least six months, over 18 years, of both sexes, registered in the SAE. Users who were not in physical and emotional conditions to participate in the survey were excluded from the study.

To perform the interviews, was initially requested the consent of the coordination of the DST/AIDS Program of Maceió through signing a term of authorization for the use of space of the institution. The survey complied with the guidelines of resolution 196/96 of the National Health Council which involves studies with humans, being initiated only after the project has been approved by the Ethics Committee of the Federal University of Alagoas (UFAL) under protocol number 015718/2011-11.

People living with HIV were discussed, according to their availability, while waiting for their outpatient follow-up consultations in health service. Those that met the inclusion criteria of the study were clarified on their objectives, procedures, risks, discomforts, benefits and confidentiality of the information, being requested then, the signature of the Informed Consent Form.

Audio-recorded interviews were conducted individually and each presented an average length of 45 minutes. These were collected between April and May 2012 by individual researchers in the dependencies of the SAE and produced from a semi-structured itinerary containing questions that allowed to characterize the subject and their diagnostics (age, sex, marital status, study time, socioeconomic conditions, naturalness, discovery time of infection and drug therapy), and sixteen questions related to representation of ARV medications, their influences on accession to ARVT, ways to confront the difficulties, known benefits, daily routine, social assistance, as well as their perceptions on the experiences, in order to respond to the proposed study.

To ensure the anonymity of the subjects in relation to the lines presented in this article, these were identified by the letter U (user initial) plus the numeric digit corresponding to the result of the realization of interviews.

The data controller is based on the analysis of content of Bardin\(^9\), which utilizes systematic procedures of description of the contents of the lines, being held through the transcription of interviews, exhaustive reading and ordering of content in descriptive groupings.

The categories were found and discussed seeking connect the cores of sense of descriptive groupings to the Theory of Social Representations of Moscovici, which features three main assumptions, namely: 1) they are socially prepared and shared; 2) they have a practical role of organizing and structuring the environment; 3) they distinguish a group, offering a sense of identity, to the extent that there is a construction of reality which is common to a social segment.\(^10\) The purpose of the analysis in the light of theory aimed to seize what the respondents think about ARVT and how each influences the perception on their treatment adherence.

RESULTS AND DISCUSSION

- Characterization of participants

The study subjects have ages between 32 and 67 years, seven are men and three women. In Brazil, despite the larger number of HIV infection be observed among men, currently, have been observed that the sex ratio has been decreasing over the years. In 1988, for every 36.5 cases among men had an affair between the female audience in Northeastern Brazil. In 2010, this ratio decreased from 1.6 men for every woman in the same region. In addition, in the region, the largest number of people with AIDS in 2010, were between 40 and 49 years of age (20.8%), followed by the age group of 30 to 34 years of age (20.4%).\(^10\)

In relation to marital status, half of the participants reported being separated, three are single, one is married and one is widower. The level of education ranges from low to medium. As to the type of occupation, four subjects are retirees, two receive benefit due to health problems resulting from AIDS, two have some kind of fundamental level and two are unemployed.

In general, the monthly income of the users is low, ranging between one to four minimum wages, being observed that the education level has bearing on this feature. In relation to the naturalness, seven respondents were born and still live in the state of Alagoas, while three claimed to be the natural city of Maceio. As for the type of religion, five users
claim to be Catholic Christians, while four of them are Protestant Christians. Only one said not to be adept to any religious entity.

In relation to diagnostic data, the time of the discovery and the beginning of ARVT among the subjects vary between six months and 16 years. These data suggest that the researched group has diagnostic and therapy time enough to reflect on the experiences that they experienced and to the verbalization of representations that attaches to their reality. As for the mode of infection, six patients contracted the AIDS virus through sexual and a user, via transfusion. Two subjects reported at the time of the interview that they didn’t know in what way were infected.

♦ Social Representations about the ARVT

Data analysis in the light of the theory of Social Representations allowed understanding the representations given by patients about their treatment with ARV, built from their experiences and perceptions, being possible the identification of phenomena described by the content that emerged from the interviews. Thus, the two categories presented relate to social representations of the participants of the study, and their discussion as follows:

♦ Category 1: Treat yourself with ARV’s encounter difficulties

Most respondents explains how the beginning and course of Pharmacotherapy were marked by the strong side-effects of drugs used in the treatment with ARV, representing something terrible, which affects their organism and mind, in accordance with the following clips:

For me, taking medication is all that affects me because my body has difficulty receiving and whenever I take I have any reaction, such as upset stomach, abdominal pain, as it generate gases. Thus, dizziness, I get dizzy, nauseous. (U1)

Early on I felt that sick. [...] Already this week I spent with the nervous system in this manner. When I dream about some bullshit I got it in my head. I spent three days with this and with a filling in the belly. Now I’m just in this manner ... these days I’ve been drunk when I go there I get a “silly” ... I hope I get better, right? (U4)

Some studies indicate that the frequency of doses, the quantity of pills and, above all, the side effects of the medicines have an important impact on the ability of users to adhere to ARVT. Some authors point out that starting treatment amounts to a second diagnosis of death due to difficulties faced in daily life with the use of medicines, representing over a painful experience to be overcome by individuals.11-12

In these cases, to take the medication can pose an aversive situation due to the occurrence of uncomfortable consequences. This process can be as a barrier capable of challenging the ability of individuals to organize their daily activities, increasing the chances of treatment interruptions, especially at the beginning of the therapy.11-12

According to the Health Ministry, the critical period for a future adherence to ARV treatment are the first six months, the occasion that requires clinical consultations and evaluations more frequently for research of the effectiveness, benefits and reactions of medicines. Adverse events of ARV involve anatomical changes, metabolic and neuropsychiatric, as well as gastrointestinal effects of varied intensities, depending on the body of each individual.13

Effects such as nausea, anorexia, headache, changes in taste, indisposition and insomnia are common in the first month of use of Zidovudine (AZT). Among the drugs in the class of Reverse Transcriptase Inhibitors Nucleoside Analogs (RTIN), AZT and didanosine (ddI) have a less favorable toxicity profile with regard to adverse metabolic effects (including lipodystrophy in time not less than one year) and hematological (anemia and/or neutropenia) associated with AZT and pancreatitis, diarrhea and peripheral neuropathy associated with ddI. Abacavir (ABC) can cause hypersensitivity syndrome and the TDF can cause nephrotoxicity in some cases.13

For the class of Reverse Transcriptase Inhibitors Nucleoside Not Analogues (RTIN), adverse effects more related to efavirenz (EFZ) tend to be exacerbated when taken concurrently with alcohol and commonly disappear after the first month of treatment, such as dizziness, sleep changes, vivid dreams, lack of concentration after ingestion and hallucinations. Therefore, its indication should be avoided in people who need to stay vigilant during the night.13

Among the drugs in the class of Protease Inhibitors (PI), the main disadvantages of some are its metabolic effects such as hyperlipidemia with hypertriglyceridemia. Nausea, malformed droppings, asthenia, abdominal pain, headache and vomiting are also reported in studies. Other less common adverse effects include hyperglycemia, liver enzyme increase and hyperamylasemia.13

As there is several adverse reactions, some patients have difficulties in identifying whether the complaints are feeling are
related to the use of medicinal products, the existence of other health problems or the fact of living with HIV, which suggests a lack of understanding and assimilation or explanation about the characteristics of the therapy by some subject that must be worked by health professionals:

I have only as side effect the pain in the bones, I always live with the pain in the bones. It's because of the medicine. No, not medication, must be the disease. Always, I am always tired, I walk a little bit I can't stand and have to stop because I can't walk more with so much pain in the bones. The legs are all shaking. (U9)

This ambivalence and uncertainty of the real causes of their health problems have also been found in the results of studies conducted in Belém, São Paulo and Juiz de Fora.9-13-4 This aspect denotes the fact that, even though the effects felt by people are not related to HIV, their representations about the disease will be influenced by this experience.

One of the criteria for the initiation of ARVT is the knowledge on the part of individuals about the early and late adverse effects of medications, its potential transience and the possibility of management of each of them, being a responsibility of health professionals the dissemination of this information to patients until the importance of adherence to treatment is understood and accepted by them.13

In addition to the adverse effects, therapeutic schemes represent a factor that allows a negative perception about the treatment because they are usually complicated due to the amount of pills and by act of taking the ARV, as well as by the difficulties of assimilation of the names of the medications and doses, a fact that requires a great commitment on the part of the patient, who needs to adapt their diet, schedules and daily pace to meet the treatment:

I don't remember the names. I just know it's a white and a yellow, are two. The white one I take one in the morning, seven o'clock in the morning and seven in the evening and the other I take the time I go to sleep. [...] It's just that I feel much difficulty taking five pills on an empty stomach, although I have to take. [...] When the day dawns, I feel sadness to swallow five pills. (U8)

And take medicine every day, you have to get used to, huh? For those who never took medicine, only used once in a while and now I'm obliged to take every day, whether you like it or not. I've a medicine, only used once in a while and now I'm obliged to take daily, whether you like it or not. I've already got used to it, is my dessert. (U9)

Studies indicate that, from the point of view of sick people, living with AIDS is permanent and that confirms due to daily routine and uninterrupted with the medicines, which implies changes in practices, living with the emotional and social impacts of the disease and its symptoms, frequent interaction with health professionals and the experience of the permanent impossibility with the hope of healing.11-12

In this category, the subject reveal, in their content, that they realize how much the drugs constitute the prison that are submitted, that their lives are directly linked to timetables, schemes and required dosages. The daily management of treatment proves to be difficult, not only by the amount of medicine or its side effects, but also by the time must be made available for the completion of the therapy. It is demonstrated the fragility of people in treatment, who know that they need him, but who are prisoners of a logic that exceeds its expertise, in the form of daily difficulty.

Other difficulties are also reported by some respondents, among them, the existence of family problems and low income conditions for buying healthy and appropriate foods:

What makes it difficult for me to take the drugs, not the side effects, is the familiar medication problem that I have. [...] Then the medication starts not to take effect, it gets more difficult to eat, I don't eat, ingest difficulty, then put to vomit and have fever, emotional fever. (U3)

You know that these antibiotics are strong and actually I don't still have a proper feeding, the way that I have to have [...] I get where I don't have to get some milk, some juice, a vegetable. It's difficult because I don't have an income. I believe that when I retire everything will be better. (U8)

The family problems and lack of financial conditions, up to feed, since the treatment requires a proper diet that can minimize the side effects, is a factor found in the results of many studies that investigate the negative aspects related to treatment adherence.8-10

As emotional strategies for confronting the presented challenges, emerged through the contents of the subjects, attitudes in order to maintain a positive attitude about their condition through the reflection of religiosity/spirituality and family support, in addition to support health service where are inserted:

And every time I think about stopping to give up on life. What helps me is my thought with God, I am in his presence. " (U4)

The service helps me a lot to talk about, encourage. Physicians, psychologist, social
worker, nurse, everybody. The nutritionist also helps me a lot when I sometimes have trouble feeding. We have a meeting here which is very good, of crafts. (U3)

Corroborating with much research, it shows that faith and family aspects and service are part of the daily life of the majority of the studied subjects and portray themselves as support for the confrontation of seropositivity and treatment, as well as in relation to how to face the everyday reality, including in the social conviviality.5-6 These aspects suggest potential mechanisms of how the media can affect the psychological adaptation in contexts of threat or damage to health.

Suffering situations of the disease and/or the imminence of death, among other problems, are motivating elements for belief in healing through faith.13 However, according to the belief system of each subject, the cure will have a different meaning. As verified, when facing difficulties with the ARVT, the importance that some interviewees attributed to healing through faith was connected not only with the feeling in God, but also with the recognition of their own impotence when faced with difficult situations. However, it is distinguished that, often, religion can incite users to quit therapy for believing that they are or will be healed:

We have to obey the laws of men here on earth, according to the Word. And doctors are used by God. I believe in this way. I know that I have HIV, but in my mind I'm not. Sometimes I cry, but then I remember that there is a God that will heal me and that at the same time I rebuke. (U8)

Whereas the references to the contents of the various difficulties with the ARV treatment by the subject are, probably, built by these to enable the representation of what is intended to assign to therapy, the individual, to sort the given object, choose a template stored in their memory for a remarkable situation, taking it as a parameter of comparison to the element to which it is submitted and deciding if this may or may not be appropriate to their reality.9

In general, for this category, the social representations theory explains the perceptions appear to consider that these are structured mediation between subject and object, from the discursive action, which is manifested through language expressed by internalization of the practices in daily life experienced, so as to allow the concept of this object acts on it and adjust to their reality, anchoring its significance in the situation of ARV treatment.16-7

In spite of the difficulties perceived by individuals about the medicines through their difficulties, the idea of a quick death sentence was being diluted when realize significant improvements, maintaining that same representation, but now postponed due to prospects that permeate the consciousness of individuals about the control capacity of the ARV, emerging hopes of a good quality of lives can be seen in the following category.

♦ Category 2: To treat yourself with ARV is feel better, is to have quality of life

Despite the feelings related to health problems and death are still preserved in the social representations of individuals with HIV, as was demonstrated in the previous categories, the advent of ARVT, on the other hand, enabled the recognition of the disease as a chronic condition compatible with survival, and especially with large preservation of quality of life.18-9

In the context of coexistence with the ARV, passed the unpleasant experiences with the treatment, the subjects believe that there's a new chance for reconstruction of daily life, building good prospects, often noted for feelings of well-being and for reversal or improvement of any health problems, such as weight gain, cessation of pain, decrease in viral load and dissipation of the feeling of death:

Through the medication I'm taking a life... quality of life, right? To take the medications, for me, means quality of life. Greatly improved. I feel new. And my dream is to make the vaccine, the cure. (U6)

At the time I took the medicines I've been modifying to best, thanks to God. I noticed that I gained more, did some tests, then it reduced the viral load. I know I can't stop taking... But, I'm getting better. […] They already told me, that there are also diseases and even worse, such as hypertension, diabetes. (U10)

In this situation, it can be affirmed that respondents attribute hope to medicines to improve their lives or even prolong them, expressed in the desire to live. This representation reflects the impact of the transformation of HIV infection acute and fatal disease to a chronic state, fact finding sustenance in the literature and on the contents of individuals to compare their condition with other chronic diseases commonly present in everyday life, such as hypertension and diabetes mellitus.18-19

The social representation in the speeches relating to the ARVT was anchored by the idea of improvement, help and hope, opposing the idea of death, as if the treatment is a chance to live. Life represents a broad concept and admits several definitions, and can refer to
the time of world conception and the death of an organism and the condition of a being who was born and has not yet died. Socially, life is a constant process of relationships in a way that the subjects live constantly in search of a meaning for the objects that surround it.

To reach the target with their perspectives on the treatment and decrease their negative sensations, interviewed users feel the need to strategize for a quality adhesion and to express, through the elaborate representations, at which level of this process they are. Thus, there are patients who no longer refer to forgetting to take medication: “I’ve been without taking medicine yes, it’s a long time, I think it was for oblivion. But now I just hang out with him, always remember”(US5). And there are patients who allege forget or delay with frequency ingestion of pills by forgetfulness or due to their social routine, although not just stop taking them:

Sometimes I forget to take. And HIV at night, sometimes I spend the time. Because there are days that I sleep late, sometimes I watch the novel, sometimes I go to church and arrive only ten p.m. When ever I remember late, I take. And sometimes, I forget, and there’s a day that I haven’t had. But it’s very hard for me to stop taking, I’m straight. (U7)

In the content presented earlier, it is evident that there is a concern with no follow-up therapy, denoting another challenge for adherence to ARVT, which refers to the ability of these to remember correctly the medications to be ingested daily, their quantities and times, factor found in several studies with similar themes.5,9,12

Under the categories presented earlier, it is possible to observe the experiments experienced by subjects in relation to their diagnosis and treatment with ARV pertaining purely biological aspects of infection and therapeutic effect, contemplating and linking too, social and cultural, culminating, through the analysis of the contents, in a series of representations able to influence positively or negatively the accession.

Users have shown that they understand, still in a shallow mode, the importance of correct use of ARV, however there are several interlinked factors, notably, to their social relationships, to their feelings, hopes and difficulties that influence in adherence, cause that can lead them to abandon the treatment if they are not worked along with health professionals.

In the field of nursing, it is necessary that the professionals understand that the representations shall be referred to the conditions that involve, while social products. In other words, the context of people’s lives represents an essential guide at the moment of health interventions because without it you can’t understand the constructs that are attributed not only the behavior of individuals and that, in this case, transformed in a continued mode.

CONCLUSION

The representations assigned by subject reveal the significance that pass through treatment with ARV is to overcome difficulties that pertain to those related to the complexity of therapeutic schemas, the adverse effects and the change in lifestyle, aiming to achieve the reaffirmation of positive representations related to perspective with the treatment, as notable improvements and consequent expulsion of the perception of death.

Thus, it is possible to note that the positive and negative significance built allow individuals prepare and adopt strategies to access conditions for overcoming or coping for better adherence to their treatment, which can and should be taken as a basis for interventions in health, since the individuals or groups express representations and give a specific definition to the represented object.9 Even this vision might come into conflict with other social groups, it is a guide to the actions and daily exchanges, because they build a consensus of reality for the different groups.

Once the phenomena of social representation built from the experiences of individuality or group are scattered around the world, expressed in the culture, institutions, social practices and interpersonal communications and mass society, being able to influence the conduct and behavior of other groups and social actors, this consideration proves valuable for determining the complexity considered by the people regarding the process of treatment adherence contributing to the operationalization of nursing public-facing studied under a brand new view and for the formulation of more effective interventions.

REFERENCES


Treatment adherence: social representations about...